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Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents', and survivors' communication preferences

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Abstract

Objective: To investigate the preferences of children with cancer, their parents, and survivors of childhood cancer regarding medical communication with child patients and variables associated with these preferences.

Methods: Preferences regarding health-care provider empathy in consultations, and children's involvement in information exchange and medical decision making were investigated by means of vignettes. Vignettes are brief descriptions of hypothetical situations, in which important factors are systematically varied following an experimental design. In total, 1440 vignettes were evaluated by 34 children with cancer (aged 8–16), 59 parents, and 51 survivors (aged 8–16 at diagnosis, currently aged 10–30). Recruitment of participants took place in three Dutch university-based pediatric oncology centers. Data were analyzed by multilevel analyses.

Results: Patients, parents, and survivors indicated the importance of health-care providers' empathy in 81% of the described situations. In most situations (70%), the three respondent groups preferred information about illness and treatment to be given to patients and parents simultaneously. Preferences regarding the amount of information provided to patients varied. The preference whether or not to shield patients from information was mainly associated with patients' age and emotionality. In most situations (71%), the three respondent groups preferred children to participate in medical decision making. This preference was mainly associated with patients' age.

Conclusions: To be able to adapt communication to parents' and patients' preferences, health-care providers should repeatedly assess the preferences of both groups. Future studies should investigate how health-care providers balance their communication between the sometimes conflicting preferences of patients and parents.

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Introduction

Current guidelines in pediatric oncology care encourage health-care providers to share relevant information with child patients to enable their active participation in decision making [1,2]. Childhood cancer patients' preferences regarding communication in pediatric oncology care seem to concur with these guidelines. Patients wish to be fully and truthfully informed and prefer to participate in treatment decision making [3]. However, observations and self-reports show that children's participation in consultations is often

limited [4–11] and is significantly influenced by parents [4,10–13]. Parents tend to manage what their child is told about the illness, and when and how this information is provided [10], mostly because they want to shield their child from potentially upsetting information [3].

The extent to which patients are satisfied with their role in communication varies between individuals. Some patients regard communication to be constrained by their parents, whereas others explicitly use their parents to facilitate the communication with health-care providers [3]. In general, communication preferences may differ

[3,10,14–17], not only within the group of pediatric oncology patients, but also between patients and parents. These communication preferences may be influenced by various factors, such as the child's age, emotional or physical state, the prognosis, or parents' and patients' pre-existing knowledge about the illness and treatment. Older children, for instance, may be more likely to be involved in medical consultations, as they are more capable of understanding the information and arguing their opinion [18–20]. However, children of the same age vary in the preferred level of involvement in medical decision making [21].

The child's emotional state may also influence communication preferences. Parents' tendency to shield their children from potentially upsetting information is likely to be stronger when their child is easily frightened. Likewise, fearful children may prefer a more passive role in information exchange and medical decision making.

When the child's situation is more threatening and when treatment decisions will have strong consequences for the child, parents are likely to prefer a more passive role in treatment decision making and tend to rely on health-care providers to make the decisions [22,23]. This is in line with studies in adult populations, in which an increasing severity of the illness has been found to be associated with a decline in patients' desire for participation in decision making [24–26].

During the course of the illness, relationships with health-care providers evolve and parents and patients gain knowledge about the illness and treatment. These developments are likely to affect their communication preferences [15,16,27]. Parents' participation in treatment decision making, for instance, changes over the course of the child's illness, ranging from a passive and cooperative role in the period following the diagnosis, to a stage of collaborative decision making later on [28].

This study aims to provide insight into the preferences of participants involved in pediatric oncology consultations regarding communication with child patients, and the variables influencing these preferences. Preferences regarding the three core components of communication will be considered [29]: the affective component (i.e. health-care provider empathy), the child's involvement in information exchange, and in medical decision making. Preferences of three groups will be investigated: children with cancer currently undergoing treatment, their parents, and survivors of childhood cancer. Survivors, who have experienced the entire course of pediatric cancer treatment, may have different views on communication than patients and parents, who are still actively involved in the treatment process.

Understanding the associations between communication preferences and characteristics of the child, the parents, and the situation may provide

indications on how to adapt communication to the needs of the persons involved.

Methods

Participant recruitment

This study is part of a larger study on communication in pediatric oncology. Three groups of participants were recruited from three Dutch university-based pediatric oncology centers. The first group (child patients) consisted of children and adolescents (aged 8–16) in active treatment for childhood cancer. The second group, their parents, was asked to participate. The third group (survivors) consisted of adolescents who had been 8–16 years old when diagnosed with childhood cancer, and whose treatment had been successfully finished in the preceding 5 years. Insufficient mastery of the Dutch language, a lag in development, treatment for secondary tumors, and being in a palliative phase of care (oncologists' evaluations) were exclusion criteria.

Recruitment of child patients and parents was executed by consecutive inclusion (April 2006–August 2008). Before the diagnostic consultation, eligible participants were informed about the study by their oncologist and were asked to participate. After the consultation, families who had given initial oral consent to participate received detailed written information about the study and informed consent forms, which could be returned to the researchers. This phased consent procedure was used to prevent families from having to read information about the study while awaiting the child's diagnosis. Families could withdraw their consent at any time, without explanation or implications for the child's treatment.

After a decisive consultation in the course of treatment (an average of 113 days after the diagnostic consultation, April 2007–September 2008), children and parents who had consented to participate were asked to complete a questionnaire containing the vignettes described in this paper. For each type of cancer, a particular decisive consultation was determined, based on the treatment protocol. For acute lymphoblastic leukemia, for instance, the consultation in which parents and child are informed about the minimal residual disease test results and the associated preferred treatment protocol was chosen as the decisive consultation.

Survivors do not regularly visit the pediatric oncology center. Therefore, survivors who met the above-mentioned inclusion criteria were selected from electronic patient recording systems in the three centers. Survivors were asked to participate by regular mail. Letters were sent from the hospital (February–July 2008) and were signed by an oncologist and the researchers. Survivors received information about the study and informed consent

forms, which could be sent back to the researchers. After receipt of the signed consent forms, questionnaires were sent out.

To increase response rates in the three groups, a written reminder was sent 2 weeks after sending the questionnaires, followed by a telephone reminder when necessary. The study was approved by the institutional review boards of the participating medical centers (METC 2005–050, AMO 05/074, MEC-2005–280).

Procedure

Communication preferences were studied by means of vignettes. Vignettes are brief descriptions of hypothetical situations, designed to be evaluated by respondents. They are constructed by combining a limited number of factors that are considered relevant for the subject under study. These factors are systematically varied following an experimental design [30], which makes it possible to analyze the effects of different types of information on the judgments given. The number of vignettes that can be presented to individual respondents and the number of factors included in each vignette are limited. However, as each respondent receives a different subset of all possible vignettes, it is possible to study a much larger number of factors and values of these factors (usually referred to as 'levels') than is presented to each respondent [31].

Based on the results of an earlier study [3] and a literature review, seven factors were selected (Table 1) and their levels were randomly combined to construct vignettes describing pediatric oncology consultations. This number of factors corresponds with the generally accepted maximum of 6–8 factors per vignette [32]. By combining these factors, 4608 vignettes could be constructed. Ideally, all vignettes need to be checked by hand for illogical combinations of factors. In practice, however, the amount of work required is usually reduced by drawing a random sample of vignettes from the total pool. In this study, a random sample of 200 vignettes was drawn and screened for logical consistency and for equally containing all possible levels of the factors. Each respondent received a unique sample of 10 vignettes, which were randomly selected from the 200. Vignettes were comparable in content for the three respondent groups, but the wording was slightly simplified for child patients (see example below).

Mike is twelve years old and just starting secondary school. He is ill. The doctors have just discovered which illness he has. At the moment Mike is feeling good, but his chance of getting better is very small. Mike is a boy who is not easily frightened. Mike's parents have little experience with serious illnesses. Mike and his parents are visiting the pediatric oncology ward, where they will be informed about his illness for the first time.

Table 1. Factors and levels used in the construction of the vignettes

Factor	Level
Main subject of the consultation	Diagnosis Treatment Prognosis Long-term effects of the illness Side effects of treatment Care and medication when the child is at home
Illness stage	Just after diagnosis In treatment for a period of time After treatment, under supervision Treatment has not had the desired effect
Prognosis	Good Moderate Poor Unclear
Child age	8 years old, in elementary school 12 years old, just starting secondary school 16 years old, in secondary school
Child emotionality	Child is easily frightened Child is not easily frightened
Child's physical condition	Child is feeling good Child is feeling bad
Amount of parents' pre-existing knowledge of the illness	A lot, because parents have searched for information themselves A lot, because parents know someone with a similar illness A lot, because one of the parents works in health care Parents have little experience with serious illnesses

Each vignette was followed by some questions about preferences related to the presented situations. Preferences regarding the child patient's involvement in information exchange and medical decision making were measured by three questions (see Table 2), for which respondents were asked to choose between two options. Participants' preference regarding the affective component of communication, which will be referred to as 'health-care provider empathy', was measured by a visual analogue scale (VAS). Participants were asked to specify their level of agreement to the statement 'The health-care provider should pay particular attention to the patient's and parents' feelings' by indicating a position along a continuous line between two endpoints. The VAS score was determined by measuring the number of millimeters from the left side of the line to the point that the respondent marked.

A pilot set of 10 vignettes was evaluated by 7 patients (aged 9–16) and 13 parents. All patients and 11 parents (84.6%) evaluated the situations described in the vignettes as recognizable. Six patients (85.7%) and 11 parents (84.6%) evaluated the information provided in

Table 2. Responses to questions about the presented vignettes (in percentages of total number of vignettes)

In the presented situation	Vignettes of		
	Patients N = 340	Parents N = 590	Survivors N = 510
Affective communication			
The health-care provider should pay particular attention to the patient's and parents' feelings ^a	80.7 (14.9)	84.5 (12.7)	76.6 (16.5)
Information exchange			
Information should be given to patient and parents simultaneously			
Yes [scored 1]	70.6	64.7	73.9
No [scored 0]	29.4	35.3	26.1
The best way to inform the patient is:			
Only to give information when the patient asks for it [scored 0]	39.4	50.6	30.6
To give information even when the patient does not ask for it [scored 1]	60.6	49.4	69.4
Participation in decision making			
The patient should participate in medical decision making			
Yes [scored 1]	77.9	68.3	67.5
No [scored 0]	22.1	31.7	32.5

N represents the number of vignettes in the corresponding respondent group.

^aReferred to as 'health care provider empathy'. Measured by a visual analogue scale (VAS). Mean VAS scores are presented, with standard deviations in parentheses.

the vignettes as sufficient to answer the subsequent questions.

Statistical analyses

The vignette method makes it possible not only to assess and compare the communication preferences of the three groups of respondents, but also to analyze the associations between specific variables (the seven underlying factors) and the reported preferences.

As each respondent provided responses to 10 vignettes, these responses are likely to be correlated within individual respondents. This implies a hierarchical data structure, with vignettes (level 1) nested within respondents (level 2). To comply with this structure, multilevel regression analyses with random intercepts were performed using MLwiN software [33], with the variables listed in Table 2 as dependent variables. Multilevel analyses did not show significant effects of clustering within pediatric oncology centers. Since respondents' preferences concerning health-care provider empathy were measured on a linear scale, linear regression analyses were performed for this variable, whereas logistic regression analyses were performed for the remaining dichotomous dependent variables. The logistic regression analyses were executed using second order Penalized Quasi-Likelihood estimation, unless stated otherwise. To investigate the association between each vignette factor and the dependent variable, over and above the effect of all other vignette factors, all factors were entered in a multivariate analysis. Pearson's correlations between the vignette factors were ≤ 0.31 , which made it possible to include all factors in the regression models. Categorical variables were

included as dummy variables. Significance of associations was tested using the Wald test.

Results

Sample characteristics

For the recruitment of children and parents, 47 families, who had consented to participate at the time of the diagnostic consultation (see Methods), were approached. Because of five single-parent families, the total sample comprised 47 children, 47 mothers and 42 fathers. Thirty-six families (76.6%) participated, providing responses from 34 children (72.3%) and 59 parents (66.3%; 33 mothers, 26 fathers). Responding ($N = 34$) and non-responding ($N = 13$) patients were comparable with respect to current age, age at diagnosis, and gender. Responding ($N = 59$) and non-responding ($N = 30$) parents were comparable with respect to age and gender.

Of the 145 survivors who were informed about the study, consent was obtained from 58 (40.0%). Fifty-one survivors (35.2%) actually participated. Responding ($N = 51$) and non-responding ($N = 94$) survivors were comparable with respect to current age, age at diagnosis, and gender.

Each participant received a unique sample of 10 vignettes, resulting in a total number of 1440 evaluated vignettes (340 evaluated by children, 590 by parents, and 510 by survivors). Characteristics of participants are reported in Table 3.

Communication preferences

Responses to the questions following the vignettes are presented in Table 2. Patients, parents, and

survivors indicated the importance of the health-care providers' empathy in the majority of situations described in the vignettes. They preferred information to be given to child and parents simultaneously in most situations. Preferences regarding the amount of information provided to patients varied. In 49–69% of situations, respondents preferred patients to receive information even without their explicit request for information, whereas in 31–51% of situations they preferred patients to be shielded from information. In most situations, respondents preferred children to participate in medical decision making.

Table 3. Characteristics of participating patients, parents, and survivors

	Patients N = 34	Parents N = 59	Survivors N = 51
Age: mean (range)	12.7 (8–16)	43.9 (31–60)	16.4 (10–30)
Age at diagnosis: mean (range)	12.2 (7–16)	—	12.2 (8–16)
Male gender: %(N)	61.8 (21)	44.1 (26)	49.0 (25)
Diagnosis: %(N)			
Leukemia	38.2 (13)	—	17.6 (9)
Kidney tumor	5.9 (2)	—	3.9 (2)
Germ cell tumor	—	—	7.8 (4)
Tumor of the central nervous system	—	—	2.0 (1)
Lymphoma	41.2 (14)	—	47.1 (24)
Bone tumor	11.8 (4)	—	11.8 (6)
Soft tissue sarcoma	2.9 (1)	—	9.8 (5)

Factors associated with communication preferences

Table 4 presents the significant multivariate associations between the seven vignette factors and the affective communication preferences. Parents preferred health-care provider empathy in case of a poor prognosis, in situations in which parents had limited experience with serious illnesses, and when parents knew a lot about the illness owing to their work in health care. Parents' preference for health-care provider empathy decreased for consultations which were mainly focused on explaining the child's treatment. Survivors preferred health-care provider empathy in case of a poor prognosis or treatment not being effective, whereas this preference decreased for patients who were not easily frightened. No significant associations were found in the group of child patients.

In all respondent groups, the two informative communication preferences were associated with child age and emotionality (Table 5). Respondents preferred 8-year-old patients (compared with 12-year-olds) and children who were easily frightened not to receive information at the same time as their parents, and to be provided with information only when they explicitly asked for it. Parents preferred 16-year-olds to receive information simultaneously with their parents and even when they did not explicitly ask for it. Parents also preferred information not to be given simultaneously in case of a poor or moderate prognosis.

Table 4. Multivariate associations between the seven vignette factors and health-care provider empathy

	Parents		Survivors	
	B (SE)	95%CI	B (SE)	95% CI
Intercept	82.8 (1.9)		80.6 (3.1)	
Consultation subject ^a				
Treatment	−2.9 (1.2)	−5.3; −0.5		
Prognosis				
Long-term effects				
Side effects				
Care/medication at home				
Illness stage ^b				
In treatment				
After treatment				
Treatment not effective			4.6 (1.9)	0.9; 8.3
Prognosis ^c				
Moderate				
Poor	1.6 (0.8)	0.0; 3.2	4.0 (1.4)	1.3; 6.7
Unclear				
Emotionality ^d				
Not easily frightened			−3.1 (1.0)	−5.1; −1.1
Parents' pre-existing knowledge ^e				
A lot; similar illness				
A lot; work in health care	2.2 (0.9)	0.4; 4.0		
Little experience	2.5 (0.8)	0.9; 4.1		

Only significant results ($p < 0.05$) are shown. Seven vignette factors were included as independent variables (see Table 1). The factors child's age^f and physical condition^g are not shown here, because no significant results were found for these variables. The same holds for the results of patients. Owing to rounding, some confidence intervals include the value 0.0. SE, standard error; CI, confidence interval. Reference categories: ^a = diagnosis; ^b = just after diagnosis; ^c = good; ^d = easily frightened; ^e = a lot of pre-existing knowledge, searched for information themselves; ^f = 12 years old; ^g = good.

Table 5. Multivariate associations between the seven vignette factors and the informative communication preferences

	Information should be given to patient and parents simultaneously						The best way to inform the patient is to give information even when he/she does not ask for it					
	Patients			Parents			Survivors			Parents		
	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)
Prognosis ^a												
Moderate			-1.4 (0.4)	0.3 (0.1-0.5)								
Poor			-1.1 (0.4)	0.3 (0.2-0.7)								
Unclear												
Child age ^b												
8 years old	-1.6 (0.5)	0.2 (0.1-0.5)	-3.0 (0.4)	0.1 (0.0-0.1)	-1.7 (0.3)	0.2 (0.1-0.3)						
16 years old			0.8 (0.4)	2.2 (1.0-4.9)								
Emotionality ^c												
Not easily frightened	1.1 (0.4)	3.0 (1.4-6.6)	1.7 (0.3)	5.5 (3.0-9.9)	0.8 (0.3)	2.2 (1.2-4.0)	1.6 (0.3)	5.0 (2.8-8.9)	0.6 (0.3)	1.8 (1.0-3.3)		

Only significant results ($p < 0.05$) are shown. Seven vignette factors were included as independent variables (see Table 1). The factors consultation subject^d, illness stage^e, child's physical condition^f, and parents' pre-existing knowledge of the illness^g are not shown here, because no significant results were found for these variables. The same holds for the results of patients in the analysis including the best way to inform the child. Owing to rounding, some confidence intervals include the value 1.0. SE, standard error; OR, odds ratio; CI, confidence interval. Reference categories: ^a = good; ^b = 12 years old; ^c = easily frightened; ^d = diagnosis; ^e = just after diagnosis; ^f = good; ^g = a lot of pre-existing knowledge, searched for information themselves.

In case of a moderate prognosis, parents preferred patients to be provided with information only when they explicitly asked for it.

In all respondent groups, preferences regarding participation in medical decision making were associated with child age (Table 6); respondents preferred 8-year-old patients (compared with 12-year-olds) not to be involved in medical decision making, whereas the opposite preference was found for 16-year-olds (parent and survivor data). Parents preferred patients who were easily frightened, and patients with a moderate or unclear prognosis not to participate in decision making.

Discussion

In this study, vignettes were used to investigate pediatric cancer patients', their parents', and survivors' preferences regarding medical communication with child patients and the variables associated with these preferences. Preferences regarding three aspects of communication were considered: health-care provider empathy, the patient's involvement in information exchange, and in medical decision making. The inclusion of three groups of participants is one of the merits of this study. This enabled us not only to investigate the unique perspectives of patients and parents [34], but also to compare the perspectives of individuals actively involved in pediatric cancer care with the perspectives of survivors, who have been successfully treated for childhood cancer.

Although patients, parents, and survivors agreed about the importance of health-care provider empathy in medical consultations, survivors indicated different situations in which empathy is needed than parents of patients in active treatment did. Whereas parents' preference for health-care provider empathy was associated with the consultation subject, the child's prognosis and parents' amount of pre-existing knowledge about the illness, survivors emphasized the importance of empathy in stressful situations, e.g. in case of a poor prognosis or treatment not being effective. Survivors' earlier experiences in cancer care and the opportunity they had to reflect on these experiences, may have influenced their affective communication preferences.

The patient's age was identified as the main factor associated with informative and decisional communication preferences. This concurs with current guidelines in pediatric oncology, which advocate an age-dependent increase in patients' involvement in information exchange and medical decision making. In the Dutch Medical Treatment Agreement, for instance, parents of children younger than 12 years have the right and responsibility to provide consent for their children's health care. Between the ages of 12 and 16, children are given partial autonomy, providing a situation of double

Table 6. Multivariate associations between the seven vignette factors and the preferences regarding participation in decision making

	Patients*		Parents		Survivors*	
	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)
Prognosis ^a						
Moderate			−0.8 (0.4)	0.5 (0.2–1.0)		
Poor						
Unclear			−1.5 (0.5)	0.2 (0.1–0.6)		
Child age ^b						
8 years old	−0.9 (0.4)	0.4 (0.2–0.9)	−2.7 (0.4)	0.1 (0.0–0.2)	−1.2 (0.3)	0.3 (0.2–0.5)
16 years old			2.9 (0.5)	18.2 (6.8–48.4)	1.1 (0.4)	3.0 (1.4–6.6)
Emotionality ^c						
Not easily frightened			1.7 (0.3)	5.5 (3.0–9.9)		

Only significant results ($p < 0.05$) are shown. Seven vignette factors were included as independent variables (see Table 1). The factors consultation subject ^d, illness stage ^e, child's physical condition ^f, and parents' pre-existing knowledge of the illness ^g are not shown here, because no significant results were found for these variables. Owing to rounding, some confidence intervals include the value 1.0. SE, standard error; OR, odds ratio; CI, confidence interval. * = Estimated by 1st order MQL. Reference categories: ^a = good; ^b = 12 years old; ^c = easily frightened; ^d = diagnosis; ^e = just after diagnosis; ^f = good; ^g = a lot of pre-existing knowledge, searched for information themselves.

consent from child and parent, while children older than 16 years have a legal status equal to their parents'. In many other countries, adolescents are also given partial or full autonomy to make decisions regarding their health [2].

Daily practice, however, often conflicts with these guidelines, as child patients' participation in consultations has been shown to be limited [4–10]. Parents tend to shield their children from potentially upsetting information [10], for instance by consulting the physician in the absence of their child [3,11]. In a recent study [3], parents indicated that their decision to be informed without their child being present was mainly based upon their opinion of the child being too young to be burdened with the information. This corresponds with the current finding of child age being the main factor associated with informational preferences. Patients' and survivors' own preferences regarding their presence during consultations vary considerably, however, and are not associated with their age [3]. Parents' preference for patients with a moderate or unclear prognosis not to participate in medical decision making may also indicate their tendency to shield children from upsetting information.

Parents' shielding tendency may contribute to a marginalization of patients in medical communication and may hamper the development of successful patient–provider relationships [10]. Open communication about the illness is generally regarded as the best policy for the child, as it improves knowledge and understanding of the illness and decreases anxiety and depression [35].

Methodological reflections

A merit of the study is the vignette method, which makes it possible to assess communication preferences of the three groups of participants, as well as to investigate the associations between characteristics of the child, parents and situation, and the reported preferences. Concerns about the vignette

method have been expressed, however, regarding the extent to which the hypothetical situations resemble realistic situations and, thereby, evoke responses similar to those evoked by the real world [36]. Unlike situations being evaluated in the real world, situations described in vignettes are composed of a limited number of factors, which may reduce the validity of responses. Vignettes are, on the other hand, recognized as particularly useful for studying potentially sensitive topics. The fact that participants respond from the perspective of the vignette character can help to distance them from difficult topics being explored and can reduce socially desirable answers [36].

Considering the stressful situation of children with cancer and their parents, the relatively high response rates within these groups (72.3% for patients; 66.3% for parents) are an asset of the study. Generalizability of the findings of survivors may be hampered by the relatively low response rate within this group (35.2%). Whereas patients and parents were personally asked to participate by their oncologist, eligible survivors were approached by mail, which may account for their lower response rate. However, no differences were found between responding and non-responding survivors regarding current age, age at diagnosis, and gender.

Conclusions

Health-care providers are faced with the difficulty of reconciling between opposing objectives, with child patients being regarded as immature and in need of protection, while also having the right to be informed and to participate in medical decision making [4]. The way in which health-care providers balance their communication between the sometimes conflicting preferences of young cancer patients and their parents in daily practice constitutes an important subject for future studies. Although the predominance of the patient's age as

a variable associated with informative and decisional communication preferences concurs with current guidelines in pediatric oncology, merely adapting medical communication to the patient's age would not suffice. Chronological age may not adequately reflect a child's ability to understand information and to voice his views. Second, earlier research has shown that communication preferences may differ, both between and within groups of parents and patients [3]. Communication preferences may also change over time, resulting from changes in disease status, relations with health-care providers, or knowledge of illness and treatment [15,16,27,37]. This is illustrated by our finding that pediatric cancer survivors indicated different situations in which health-care provider empathy is needed than parents of patients in active treatment did. To be able to adequately adapt medical communication to parents' and patients' preferences, health-care providers should repeatedly assess the preferences of both groups.

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